

**OVERVIEW & SCRUTINY BOARD**

**6 MARCH 2007**

**MIDDLESBROUGH & ESTON HEALTH SCRUTINY  
JOINT COMMITTEE**

**RESPITE AND PALLIATIVE SERVICES FOR CHILDREN WITH LIFE  
LIMITING ILLNESSES – FINAL REPORT**

**PURPOSE OF THE REPORT**

1. To document the evidence received by the Joint Scrutiny Committee (JSC) in its review of the above topic.

**BACKGROUND**

2. There has rarely been a time when Children's Services have a higher public profile. Advances in medical technology also mean that a greater number of children are surviving longer with conditions which they may not have survived in the past. Against this backdrop, the Joint Scrutiny Committee felt that it would be an opportune time to review the services currently available for this cohort of children and the relationships between local authorities, NHS agencies and the Voluntary and Community Sector.

**TERMS OF REFERENCE**

3. In respect of Respite & Palliative Services for Children with Life Limiting Illnesses:
  - a) To examine the current level of service provision.
  - b) To research the prevailing national policy on the subject.
  - c) To establish what duties, if any, are placed upon the local NHS bodies and local authorities in relation to the subject.

- d) To establish the current level of need for such services and whether the need is being adequately met.
- e) To establish whether there is a need for development in current service provision and to what extent any required developments can be achieved.
- f) To take evidence from as wide a range of stakeholders as possible.
- g) To prepare, agree and publish a report detailing the evidence considered and making any recommendations considered appropriate to put to the relevant organisation (s).

## **EVIDENCE GATHERED BY THE JOINT SCRUTINY COMMITTEE**

- 4. At its meeting on 13 September 2005, the JSC considered evidence provided by Middlesbrough PCT.
- 5. The JSC heard that palliative and respite care for children had just recently come onto the agenda as a major topic, with the PCT having a clear responsibility to commission/provide adequate healthcare services. It was confirmed that those services commissioned could be located at home, within a hospital or hospice setting.
- 6. The JSC heard that the definition of Palliative care was as follows.
- 7. "The active total care offered to a patient with severe progressive life limiting illnesses and their family, when a curative treatment is neither possible nor appropriate and the focus of care is quality of life and the alleviation of distressing symptoms"
- 8. Respite Care was defined as:
- 9. "Short term, temporary care provided to people with severe disabilities, chronic or terminal illness, and is designed to give families a break from the stress of daily care giving"
- 10. The JSC noted the recent emergence of national guidance such as the *Children, Young People and Maternity Services National Service Framework (NSF)*, *Improving Outcomes in Children & Young People with Cancer 2005* and the National Institute for Clinical Excellence's *Improving Supportive and Palliative care for Adults with Cancer 2004*.
- 11. The JSC enquired as to whether such policy developments had created extra responsibilities for the PCT to assume. The JSC heard that whilst the above guidance documents had clarified the standards and what was expected of PCTs, it was not felt that they had increased the responsibilities.

12. The JSC heard that a number of infants with a life limiting illness were treated at specialist regional centres (such as Newcastle and Leeds) and it was often considered in some areas as a reactive service.
13. Further, the JSC heard that the PCT was keen to ensure a more seamless service was on offer within the locality and was undertaking a mapping exercise, to identify children with a complex or additional healthcare need within the Middlesbrough PCT area.
14. The JSC heard that the emerging findings from the initial work done had highlighted two specific gaps in service provision. Those were, respite care (particularly for children without a learning difficulty) in day care, residential care, within the family home and the transition into adult services.
15. In terms of contribution to services, the JSC heard that with the exception of the James Cook University Hospital Paediatric Palliative Care Team, the PCT contributed to all NHS services through relevant contracts.
16. It was confirmed to the JSC that the services provided by the voluntary and community sector were paid for on a cost per case basis and a similar agreement would be taken forward to the Service Level agreement being arranged between the PCT, Zoe's Place and the Butterwick Hospice.
17. The JSC also had it confirmed that the PCT was in the process of producing a strategy for palliative care services, a part of which would be to undertake full health needs assessment, following which the appropriate services would be put in place.
18. At the meeting on 2 March 2006, the JSC took evidence from Zoe's Place Children's Hospice.
19. The JSC heard that Zoe's Place had entered into a Service Level Agreement with Middlesbrough PCT and Langbaugh PCT. The JSC was advised that the SLA committed the PCTs to pay £55 per day for day care and £110 per 24-hour period. The JSC had it confirmed that those figures, were by no means the full costs of placements and were only to cover the healthcare needs of service users. The PCTs are not responsible for social care of service users.
20. The JSC commented that the figures outlined above looked quite low for the amount of care, which would be required. Zoe's Place agreed with that view, although the JSC heard that the SLA was a start and that the income was better than what they had been getting previously.
21. The JSC heard that there were hopes of arranging a similar type of SLA with local authorities to contribute to service users social care needs.
22. It was confirmed that Zoe's Place is regulated by Ofsted for educational matters and regulated by the Healthcare Commission for healthcare purposes.

23. On the subject of the SLA, the JSC was told that it was a step in the right direction and created an income stream that was not there previously. The JSC was further told that, in the view of the witness, there is a lack of central government funding for hospice services, despite the current emphasis on the rights of and services for children.
24. The JSC heard that, as no SLA exists between Zoe's Place and local authorities, if there is a referral from local authorities, no funding is attached to that.
25. At the conclusion of this meeting, the JSC agreed to hold a meeting whereby evidence would be gathered from an expert in VCS involvement in the provision of public services and the financing of those arrangements. The JSC felt it very important to consider the role of the VCS in this subject. During the JSC's initial evidence gathering, it became clear to the JSC that the VCS was a significant part of service provision in relation to Children's Services. It was the view of the JSC that as these types of services continued to develop and change to meet need, the local VCS would have a substantial role in service provision. Accordingly, the JSC felt it vital to consider the subject, the role of the VCS, its relationship with the statutory sector and relevant national policy.
26. At its meeting on 13 April 2006, the JSC opened the meeting with hearing from a representative of Zoe's Place, regarding the nature of the SLA with Middlesbrough & Langbaugh PCTs. It was confirmed that the SLA was not drafted on the basis of full cost recovery and set a day care rate of £55 and a 24 hour period rate of £110.
27. The JSC felt that this agreement was, in effect, 'on the spot' purchasing and constituted a better deal for the PCT than for Zoe's Place.
28. The JSC then moved on to take evidence from the Middlesbrough Voluntary Development Agency (MVDA).
29. The JSC heard that most of the MVDA's support was provided for smaller organisations in and around the setting up of ventures, although through national funds it was also involved in developing VCS organisation's infrastructure and capacity.
30. The JSC enquired as to why the VCS should be used in public service delivery. It heard that evidence indicated that the services provided by the VCS provided high quality and cost effective services, despite an often held misconception that it was a cheap and less effective option.
31. Mention was made of the VCS capacity to understand in great depth the areas in which they operate and their willingness (and greater freedom) to innovate.

32. A number of issues were raised with reference to the VCS' involvement in public service provision, which would impact on the success (or not) of the VCS' involvement.
33. It was said that the length of contract was an important consideration in the interests of service stability and the ability to plan for a service's development.
34. The JSC discussed the concept of full cost recovery. It was stated that all communication emanating from central government championed the importance of full cost recovery, although in reality it did not tend to happen.
35. The JSC heard that without acceptance of the principle of full cost recovery, the VCS was always going to be placed at a disadvantage. This is because it would be left with providing a loss creating service, or at very best, having to make up the shortfall through general funds/reserves or fundraising. It was noted, however, that there is an element of 'beggars not being able to be choosers', as partial cost recovery may be the best deal that a VCS organisation is offered.
36. In terms of moving the VCS agenda forward, the JSC were interested in what could be done. The importance of properly developing and implementing Compacts was stressed as key, as well as developing procurement processes using the North East Centre of Excellence in Procurement.
37. The possibility of statutory sector organisations having a dedicated post of a VCS champion was discussed as well as a need for such organisations to develop their understanding of the VCS.
38. Following a discussion of the VCS, the JSC moved onto hearing evidence in relation to local authorities' responsibilities towards social care, in the context of the Children's Services National Service Framework.
39. The JSC heard that in recent years, the way in which disabled children were cared for had changed dramatically in terms of hospitals, residential care and the majority of whom were supported at home. As a result of legislation, specialist social work teams for children with disabilities had been created, former homes for children had been developed and become resource centres for children and the Direct Payments system had been established.
40. The JSC heard that each child was assessed according to specific criteria and a care pathway was considered for them. Parents have access to good quality information for general purposes and to specifically assist them in considering whether to take up their entitlement to utilise Direct Payments.
41. It was stressed that the local authorities' specialist teams tend to work with children who have moderate to severe disability and are likely to require support services into adult life.
42. The JSC heard that the whilst the take up of Direct payments had increased in recent months, it can be very stressful for parents, who do not necessarily

want or need the responsibility of commissioning on behalf of their child/children and being a de facto employer. If such was the case, it is likely that the case would be referred through to a local authority panel, which would commission services on their behalf. A further complication to that was the fact that, it is apparently difficult to source staff for direct payments.

43. The JSC heard about a number of facilities and services that the local authority provide including social work support, resources centres, South Tees Home support, specialist foster care, services purchased by the local authority and direct payments.
44. On the subject of Direct Payments, the JSC had it confirmed that uptake had increased, although there was a feeling that demand had possibly not been as well mapped as it could have been. In addition, it was difficult to persuade people to leave mainstream services.
45. The JSC was told that if it was the most appropriate service for an individual, local authorities would pay full cost, although it would be on a case by case basis and not the on-going contract basis which had been discussed as being most beneficial to encouraging a vibrant VCS. It was also noted that Direct Payments do create a market and in any market, there will be winners and losers.
46. The JSC felt it was worth highlighting that there is no written standard or criteria as to what constitutes health care and what constitutes social care around children's services, as there is with adults. This is something which surely breeds an element of confusion.
47. At its meeting on 26 May 2006, the JSC commenced by hearing evidence from the Middlesbrough Voluntary Development Agency about prevailing national policy on the involvement of the VCS in public services.
48. The JSC heard that the Government's position is that when the VCS provide services for the statutory sector, full cost recovery should be granted and actively pursued. Historically, the VCS has only ever received part cost recovery and has been expected to make up the shortfall, nonetheless the JSC heard that Government policy was demonstrating a clear shift towards embracing the notion of full cost recovery.
49. The JSC heard that in the current climate, when more and more services are being provided through the VCS, the reality is that full cost recovery is not being embraced as enthusiastically as central government are espousing its value.
50. On reasons for this, the JSC heard that the VCS needs to improve its tendering processes and specifically, it has a tendency to underestimate the cost of delivering a service, in the hope of being successful. The JSC heard that this can be counter productive as it could burden an organisation with a loss creating contract.

51. The JSC heard that there is nothing wrong per se, with the VCS acknowledging the fact that they have running costs and that contracts would be a key method of paying for those running costs, as they would in any venture. In the view of the MVDA, that view needs to get across to the VCS in a more audible fashion than it has done to date. It was heard that the Draft Middlesbrough Compact includes the aspiration that contracts with the VCS should be on a full cost recovery basis, although there are no extra resources from central government to assist in funding this change in philosophy. It was felt noteworthy to mention, however, that Commissioners are also facing financial constraints.
52. The JSC heard that local authorities are not in a position to fund everything they would perhaps like to and are required to make value judgements on what they fund/support.
53. The JSC heard that when it comes to arranging for services to be provided to individuals depending on need, services are funded on a case by case basis and are often on a partial cost basis. Consequently, spot purchasing would appear to be the prevailing methodology of securing required services.
54. The JSC felt that there was a principle involved in the idea of full cost recovery. The JSC expressed the view that anything other than full cost recovery would not be entertained in any other sphere of activity, although there was an implication that it was good enough for the VCS. The JSC expressed the view that if a service is suitable for purchasing (even on spot basis) then it was appropriate to pay the full cost of that service.
55. At the conclusion of the consideration of the evidence gathered at this meeting, the JSC expressed a wish at the next meeting to speak with senior political and managerial leadership on the review's topic and the level of engagement with the VCS.
56. At its meeting on 18 July 2006, the JSC heard that the way families with needs were treated had changed dramatically over recent years, with people being offered significantly more support at home, unless they were part of a high-risk group. Indeed, it was said that supporting people at home was an increasing area of activity.
57. The JSC heard that in addition to this, there has been a large increase in the amount of direct payments. This allows individuals and/or their families to select and pursue their own services, in effect acting as micro commissioners. This supported the point that the local authorities were less able to source a wide range of services on behalf of their local communities, as with direct payments individuals and/or their families bought directly on their own behalf.
58. The JSC heard that when it comes to service providers, there is an approach which local authorities are obliged to pursue. If a need is identified, officers in the local authority will consider the required service specification, commence a tendering process, which results in the awarding of a contract, and then the contract is monitored.

59. The JSC heard that in this respect, there is a fine balancing act for local authorities to perform between securing an appropriate quality of service and ensuring that value for money demands are met.
60. The JSC enquired as to how the Compact notions of full cost recovery and contributing to the sustainability of the Voluntary & Community Sector (VCS), were observed within the tendering and awarding of contracts process.
61. The JSC heard that business viability health checks with commissioned organisations were conducted as part of the due diligence process. Further to that, the Compact principles would be part of a tendering process, although it was highlighted to the JSC that the ultimate consideration was the quality of the service on offer and the best quality provider would be the one selected, irrespective of the 'sector' it came from.
62. The JSC considered Zoe's Place Children's Hospice as a case study. It heard that the Service Level Agreement (SLA) between the PCT and Zoe's Place for care given to children, equates to around one third of the total cost of the provision of that care.
63. The JSC heard that the PCT would be, at this stage, unwilling to enter into a full cost recovery arrangement with Zoe's Place as it is very expensive and not particularly cost efficient. The JSC heard that there are real financial savings as well as benefits for the child, in keeping the child at home and delivering the care there.
64. At this stage, the JSC heard that as a matter of good practice, any child who comes into contact with the service is fully assessed, their needs discussed and finally addressed through a personalised package of care.
65. Nonetheless, Members were informed that current professional thinking was that it was not best for children to be in residential units and consequently, available resources have been moved towards keeping children in the home environment, wherever possible. In addition, foster carers are also available for care, should respite be needed. The JSC was informed that it was felt such arrangements were more beneficial for the child involved, as opposed to being accommodated in a residential unit for any given timeframe.
66. The JSC heard that if parents choose to not take up their right to direct payments, a child goes to the Children's Panel. This Panel will then consider the needs of the child (and possibly wider family) to construct a care package, which best meets those needs. The JSC was told that the feeling of the professionals involved in this process feel it works and delivers the best outcomes for the child. It was confirmed that through this process, neither Redcar & Cleveland Borough Council nor Middlesbrough Council had referred a child to Zoe's Place.
67. It was emphasised to the JSC that, in the view of the witnesses, children are much better being cared for at home, so long as that accords with the wishes



of the parents. Reference was made to current professional advice and research overwhelmingly indicating that being at home is more beneficial to children, rather than being in 'an institution'.

68. The JSC enquired about respite care, giving primary carers a break and how that is provided. The JSC heard that respite care is viewed as very important, although it has to be considered in conjunction with the needs of the child. Respite can, in fact, often be sourced from within the child's own extended family. It was emphasised that no children had been referred to Zoe's Place as a result of the deliberations of the Children's Panel.
69. On the subject of the expenditure of public funds, it was confirmed to the JSC that a need had to be identified before public money was expended. Further to that, if a particular need is identified, the need and accompanying funds is attached to the individual. Local authorities are not in a position, the JSC heard, to fund any establishment or service on an ongoing basis, 'in case' it was needed following an assessment of a particular child.
70. It was emphasised to the JSC that should a child's case progress to the Children's Panel, whilst the Panel listened very carefully to the views of the family, it was the Panel's decision. Further, it was emphasised to the JSC that the decision of the Children's Panel was based on clinical/social care need and not the wishes or wants of the child and/or family.
71. The JSC observed that national policy in relation to the VCS encourages the concepts the full cost recovery, moving away from spot purchasing and supporting the vitality of the local marketplace, with the VCS being an active part of that.
72. The JSC feels that this governmental ethos is at complete odds with the notion of funding individuals and direct payments. The JSC holds the view that by funding individuals and supporting direct payments, spot purchasing will continue to prevail. On this point, the JSC felt that central government was not being consistent, or particularly helpful in advising local government on their dual role of 'place shaping', creating a local market place and protecting the interests of children.
73. The JSC suggested that it would be desirable if the VCS was involved early enough in the process, so that if families were considering taking direct payments, they were aware of the full choices available. On this point, the JSC felt there was something of a contradiction, which emanated from current central government policy. On one hand, direct payments and the funding following individuals inevitably encourages a spot-purchasing environment, which is not conducive to a sustainable VCS in the locality. The JSC felt that as a natural consequence of the above, there may not be the choice available for individuals and/or families when they come to review options and whether to take up direct payments.
74. In so far as tendering processes were concerned, the JSC heard that tendering processes were open to the VCS and that they were free to submit

tenders. It was felt that when establishing a tendering process, it would be desirable to take account of the VCS' limitations in having adequate administrative support and accordingly to make the tendering windows of sufficient length to allow submissions to be arranged and made.

75. Moving away slightly from service provision, Members enquired about the involvement of the VCS in service planning. It was said that the VCS will be involved with the Children's Trusts when established and that there will be VCS representation at that level. Further, it was acknowledged that the Local Strategic Partnership provided a means by which joint working could be developed further and opportunity to inform the strategic decision making process of the services available which included the consideration of smaller organisations which existed to meet specific needs.
76. The JSC asked if the current level of VCS involvement was not simply tokenism. The JSC heard that the witnesses did not think so. It was said that within Redcar & Cleveland and Middlesbrough the VCS is very active and a number of excellent services are provided by the VCS, including one for young carers, the funding for which was matched through core funding. The JSC heard that Middlesbrough was particularly good at involving children and getting their views via the VCS.
77. Nonetheless, the JSC emphasised the point that if spot purchasing continues as the predominant model, the logical conclusion is that VCS will struggle to continue, as they will not have sufficient funds survive and offer a credible option.
78. The JSC expressed the view that the approach towards the VCS indicated that, commissioning was a rather haphazard process. The witnesses rejected this view and explained that the commissioners had a long-term view as well. It was emphasised that the local authorities could not be too tied to any one service provider, irrespective of which sector they were from, as it is important that they have the freedom to decommission services when they are not required, as to continue would represent a poor use of money.
79. The JSC learnt that private companies operated the Direct Payment services in Redcar & Cleveland and Middlesbrough Councils. It was the view of the JSC that it was a question of principle as to whether the tendering process for such should be simply about the effectiveness of the tender or whether it should be about wanting to support the local VCS when local authorities are in a position to do so.
80. In conclusion to the evidence gathering, the JSC emphasised that there was nothing in current direct payments or tendering arrangements, which would bar elements of the VCS. The only stipulations were that there should be a legitimate and identified need and that direct payments cannot pay for healthcare, which is separate and distinct from social care.
81. The JSC met on 29 September 2006 to consider the evidence it had gathered to date. The view of the JSC was that whilst it had gathered a great deal of

information on the topic, it was felt that the Panel's information was lacking in two respects. Firstly, the Panel was aware that government guidance was due to be published in relation to the role that hospices can play in the local health economy and how such establishments are funded. The Panel felt that it would be prudent to consider the contents of that central government document before coming to any firm views.

82. Secondly, it was felt that the JSC should speak to procurement professionals in both local authorities about procurement practices, relationships with the VCS and the environments in which procurement arrangements presently operate.
83. The JSC waited for the publication of the government document, so it may take account of it, although it did not materialise from central government by Christmas 2006. As a result of this, the JSC felt it important to press ahead with the review and gathering the necessary remaining evidence.
84. To that end, the JSC met on 24 January 2007 and took evidence from procurement professionals from both local authorities in relation to how procurement of services is structured, how the VCS is engaged with and the policy environment in which it operates.
85. At the start of the meeting, the Chair explained that the JSC was interested to hear whether the local VCS was given an opportunity to get involved in the provision of services. Further, to what extent local authorities were playing a role in encouraging a local marketplace, including a plurality of potential services providers.
86. Mention was made of Middlesbrough Council's 'Compact', a document relating to the Council's involvement with the VCS, which is presently in a draft stage, which outlined the Council's commitment towards the VCS.
87. It was confirmed to the Panel that Middlesbrough Council's tenders are always sent to the Middlesbrough Voluntary Development Agency (MVDA), which they then distribute. This provides an opportunity for local organisations to bid to provide services. The JSC heard that a recent supervised contract for transport provides an example of this process in operation.
88. The JSC was interested to explore the concept of stimulation of a local marketplace and a local authority's role in that. It was stated that the VCS are Members of the Children's Trust and that the advent of Children's Trusts may bring about a more diverse market from which to purchase services.
89. The JSC enquired as to the proportion of Middlesbrough Council's Children's Services contracts which have been awarded to the VCS. After the meeting, the JSC was advised in writing of the detailed picture. It was confirmed that during 2005/6 10 services were provided by the VCS, on behalf of Middlesbrough Council's Children Families and Learning Department. This works out as 28% of the total number of services (either contracted out or provided in house), with a total fiscal value during 2005/6 of £485,749. This

equates to 10% of the total value of services (either contracted out or delivered in house) and the average length of contracts with the VCS is one year. It was confirmed that 2006/7 figures were not available, although the figures above for 2005/6 provide a very useful snapshot of the current state of play.

90. The JSC mentioned the concept of spot purchasing, which it has previously heard seemed to be the dominant model in the provision of services. It was accepted that spot purchasing plays a substantial role in the local marketplace, albeit at times through necessity. The JSC heard that the Comprehensive Spending Review may help as there was a possibility that it could bring about three year budgets. This may be beneficial for service planning, developing the marketplace and contracting, as annual budgets make it difficult to plan future spending and service planning with any real certainty.
91. It was confirmed that Middlesbrough Council is presently considering the state of Children's Services in connection with disabilities, against the backdrop of the advent of Direct Payments. It was explained to the JSC that Direct Payments can impact significantly on a service's ability to plan. Further, it was felt that the present budget is not appropriate to fund service developments and Direct Payment commitments.
92. The JSC moved on to consider the initial evidence from Redcar & Cleveland Borough Council. The JSC heard that all contracts in relation to Children's Services are with the VCS and that all are block contracts. The point was made that nothing is spot purchased, with the exception of residential care, which is very difficult to plan for, as it very much depends on the needs of the individual. It was confirmed that around 90% of Children's Services contracts are with the VCS, which equates to around £1.3m in annual financial worth. It was established that this equates to substantially more than 10% of the overall budget, although it was stressed that this did not include residential placements.
93. In terms of its relationship with the marketplace, it was confirmed that if the Council identifies an area of need, it will go out to tender to enable the meeting of that need. It was outlined to the JSC that some services/organisations would not exist if it was not for local government led demand, such is the lack of finance and other viable markets. It was highlighted, therefore, that in such circumstance, local government could stimulate a marketplace. It was stated that local authorities can sometimes enter joint arrangements for certain service areas, which provides enough of a financial incentive for a marketplace to be stimulated. The JSC heard that this has been done in some circumstances between the Tees Valley local authorities.
94. The JSC enquired as to how a need is identified. It was confirmed that needs are highlighted as a result of individuals having care plans completed. If a service is not available in the Borough, a discussion is required as to whether

the service should be stimulated, whether it is needed in suitable quantities to be stimulated and whether it is affordable.

95. The JSC enquired as to where individuals/families views fit into establishing need. It was stated that, of course, people's views are taken into account, although a distinction needs to be made between needs or wants. Further to that, is a much more fundamental question as to whether local government should fund measures which may not be of strict need, but make people's lives more manageable. It was highlighted that if it is a service which the local authority is statutorily obliged to provide, there is no option in the matter and the service must be provided. Alternatively, whether services should be provided which go above and beyond strict need is a policy matter for Elected Members to provide direction on.
96. At this point, the JSC entered into a roundtable debate on the matters at hand. In relation to respite and palliative care for children, it was stated that the expected government guidance on hospice provision may provide direction, together with the establishment of a Children's trust. Nonetheless, the point was made that hospice care is a health service, the responsibility over which is that of the local PCT's.
97. The JSC enquired as to whether there was an absence of will to develop hospice services. It was confirmed to the JSC that if such services were utilised, they would be funded on a spot purchase basis as opposed to a block type arrangement. The JSC heard that a move to encourage the development of a local marketplace, would be one which should be politically led. If there was a budget to fund such developments, the services would act on those instructions, although there is no such budget in place presently.
98. The point was made that Direct Payments may assist in developing or stimulating the marketplace, although it should be noted that presently, there is no dedicated budgetary provision for Direct Payments. To clarify, that means that Direct Payments are required to be taken out of core funds. The JSC understood that to exist within such a regime and not affect contract funding it required the service to find savings elsewhere and this could mean in terms of staff. The example was given from Redcar & Cleveland Borough Council where domiciliary staff has had to be reduced, as more people take up Direct Payments.
99. The JSC was interested to learn that if people elect to take Direct Payments, they are not permitted to purchase services from local government and are required to purchase from the VCS or the Independent Sector. The logical conclusion of this is that local government is being asked to fund two different streams from one central pot, i.e. the provision of services and Direct Payments. The JSC accepted that such a policy environment inevitably impacts upon a given local authority's ability to shape/influence the composition of the local marketplace. It was explained how the local authority is having to be a commissioner and a provider. The point was made, however, that within Direct Payments it is increasingly playing the role of a facilitator, although still with a duty to check services are of the requisite quality.

100. The JSC made enquiries as to how the local marketplace could be stimulated. The point was made that from the position of the local authority, a decision on commissioning a specific service is not a purely financial exercise, there is also a very important consideration around the quality of the service available. The JSC heard that 'social benefit' clauses were becoming increasingly common, which would often be weighted in the favour of keeping people and resources within the local area, which would benefit efforts to stimulate a local marketplace.
101. The JSC also heard that the oft-held perception that the VCS are not involved extensively in service provision needs to be challenged, as it is quite often the sole service provider. The JSC felt that such a lack of knowledge or understanding of the VCS' involvement highlighted a need for better information to be captured and presented.
102. It was felt that the growing influence of Compacts would lead to a better stimulation of the marketplace, although it was noted that the idea of full cost recovery becoming the norm was still a long way off.
103. The JSC heard from the witnesses that a lot of the engagement of the VCS is actually quite patronising and that central government's understanding of the VCS is quite basic. The vast majority of VCS organisations are run along clear business models and the statutory sector should treat them as such.
104. The JSC heard that, on the whole, local government accepts that it is becoming more of a commissioner, although it is very important for it to have proper intelligence about what is needed in the locality to stimulate the local marketplace accordingly. The JSC accepted that such an approach was much more desirable than a local authority commissioning services 'blindly', without proper intelligence on what the locality needed. Nonetheless, it was accepted that when Direct Payments are added to the equation, it becomes a very complex picture.
105. It was confirmed to the JSC that there is presently no local government funding for respite care as such. If parents or other family members decide to self refer to a given hospice-type facility, there is no funding available for respite. It was emphasised to the JSC that no funding would be available until a social work professional had identified a need. To clarify, local government cannot provide a service if no assessment has taken place. Again, it is a question of what is *needed* by the individual, in the view of professional officers.
106. Whilst the JSC accepted that certain procedures were in place to assess need through a staged process, it was unclear as to how need would be assessed in a crisis-type situation. The JSC considered the example of when a family unexpectedly presents at a hospice-type facility asking for help. It was unclear as to how Social Care would find out about such people. The JSC considered that referral/information-sharing protocols might be appropriate to facilitate this and ensure some children do not fall through the net.

107. Reference was made to the joint panels, which meet to establish a child's needs. It was reiterated that hospice care is defined as a healthcare need and as such a NHS responsibility. This was confirmed as a national government policy direction and in evidence of that, it is the NHS which receives funding for hospice care.
108. The JSC questioned as to why social care would not get more involved in the provision of hospice type care for children. It heard that aside from the national policy direction outlined above, local government did not receive the money for the service and consequently there were very real budgetary constraints.
109. The JSC heard about the existence of a joint panel in the Stockton on Tees Borough Council area, whereby healthcare and social care needs of children are considered at the same time, with access to pooled budgets. The JSC advanced the concept of a joint south of Tees panel, which could meet to establish the health and social care needs of children similar to that in Stockton.
110. The JSC accepted that budgetary realities played a significant role in the matter, although there was a responsibility on politicians, supported by senior managers to set the budgets and budget priorities they felt appropriate.
111. The JSC considered the concept of a pooled budget arrangement between local authority and PCT to fund care for the cohort of children requiring such types of care. The JSC considered that a south of Tees protocol could be established which would outline the head of terms and then each locality could provide the funds for 'its own children', whether they needed health or social care.
112. The JSC considered that when one thought of the amount of children this would apply to, it was actually quite low. The JSC felt that such an arrangement could be implemented if there were political instructions as such and the organisational will to do so.
113. The JSC considered that this was especially so given the demographic challenges which will be presented to local authorities and the local NHS in the near future. Advances in medical technology mean that more infants are surviving childbirth with conditions, which they previously may not have survived. Whilst this is to be welcomed, it does cause a further strain on public services which needs to be met. The JSC felt that as services to children with disabilities would be a growing area of demand, there was a need for reflection on how joint local government and NHS structures could best meet that demand. The JSC felt it entirely appropriate that Elected Members, as the ultimate policy makers within any given local authority, lead this period of reflection and debate.

114. In addition, the JSC has heard on more than one occasion that national guidance would be welcome to clarify the roles of local government and the local NHS in considering services provided for this cohort of children.

## **CONCLUSIONS**

115. The Joint Scrutiny Committee concludes that there seems to be a contradiction between central government policy in relation to this subject area. On one hand, service users (and their families) are encouraged to act as micro commissioners by being given access to Direct Payments and individual care plans seem to encourage spot purchasing. On the other hand, local authorities are encouraged to act as 'place shapers' and stimulate a local marketplace, providing a plurality of providers. The JSC feels this dual expectation/duty is unhelpful and should be clarified by central government.
116. The Joint Scrutiny Committee concludes that medical advances dictate that children with life limiting illnesses will be a group growing in number. It is felt that consideration needs to be given now as how best to structure the health and social care services to meet the needs of these children. The absence of central government guidance in relation to respite and hospice provision is particularly unhelpful.
117. The Joint Scrutiny Committee concludes that children and their families do not necessarily see or understand the distinction between health and social care organisational responsibilities and boundaries. As a result of this, it would be advantageous if future service developments were joint health and social developments wherever possible.
118. The Joint Scrutiny Committee understands that health and social care assessments are required to be assessed on need. Nonetheless, there is a concern that a cohort of people will not receive assistance as they are not deemed to be in need, when the problems faced are very real to them.
119. The Joint Scrutiny Committee concludes that it would be advantageous to service users and the wider local health and social care economy if a local marketplace of providers, including the Voluntary & Community Sector as equal contractual partners, could be stimulated.

## **RECOMMENDATIONS**

120. That the local health and social care economy lobbies central government to release guidance on the policy direction in the looking after of this group of children and organisational responsibilities as their numbers become greater.
121. That the local authority considers developing policy around the supporting of a local marketplace of service providers, particularly to support this cohort of children.
122. That the local health and social care economy commences a debate, led by Elected Members, on the type of services required to address the needs of



this cohort of children. Further, to consider the extent to which these services can be developed on a joint health and social care basis, with pooled budgets where appropriate

123. That the Joint Scrutiny Committee's successor body revisits service provision in this area, at an opportune time in the near future.

## **BACKGROUND PAPERS**

National Service Framework for Children, Young People and Maternity Services.

**Councillor E. Dryden**  
**Chair, Middlesbrough & Eston Health Scrutiny Joint Committee**

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